

Identifying neurodevelopmental disorders: The complexity of Fetal Alcohol Spectrum Disorders (FASD)

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#greycells

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**NHS Ayrshire & Arran Fetal Alcohol Advisory and
Support Team**

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Alcohol Facts and Figures



What is the impact of Alcohol in Scotland?

- £3.6 billion spent every year on alcohol related harm, £1 billion, more than Scotland's entire education budget!
- 20% more alcohol is sold per adult in Scotland each year than in England and Wales.
- Over 16,000 places to buy alcohol in Scotland – 16 times more outlets than GP practices!
- In 2015 wine sales in Scotland reached their highest level for over 20 years.
- 1 in 6 women in Scotland are drinking to potentially harmful levels.



Attitudes to women drinking



Drinking culture in Scotland



In 2015, almost three-quarters of alcohol purchased in Scotland was sold in supermarkets and off-licences.

Self-reported figures recorded that 20.8 units of alcohol, per adult, per week are consumed in Scotland, compared with 17.4 units for England and Wales.

However, these self-reported figures only account for 55% of total alcohol sales in Scotland.

Are we not being honest about the amount we drink or are we still unaware of the units we consume?

Source: NHS Health Scotland: Scottish Health Survey



New alcohol guidelines



The Chief Medical Officers' guideline for both men and women is that:

- You are safest not to drink regularly more than **14 units per week**, to keep health risks from drinking alcohol to a low level.
- If you do drink as much as 14 units per week, it is best to **spread this evenly over 3 days or more**.

What is a **unit of alcohol**?



Units of alcohol

 <p>Single Gin & tonic ABV 40% 1 UNIT 120 calories</p>	 <p>Sambuca shot ABV 42% 1 UNIT 123 calories</p>	 <p>Pimms ABV 25% 1.3 UNITS 156 calories</p>	 <p>Alcopop ABV 5% 1.4 UNITS 160 calories</p>	 <p>Red wine (125ml) ABV 12.5% 1.6 UNITS 85 calories</p>
 <p>Bottle of lager ABV 5.2% 1.7 UNITS 145 calories</p>	 <p>Double whisky ABV 40% 2 UNITS 128 calories</p>	 <p>Mojito ABV 40% 2 UNITS 150 calories</p>	 <p>Champagne ABV 11.5% 2 UNITS 133 calories</p>	 <p>Cosmopolitan ABV 12.5% 2 UNITS 151 calories</p>
 <p>White wine (175ml) ABV 12.5% 2.3 UNITS 244 calories</p>	 <p>Pint of bitter ABV 5% 2.8 UNITS 288 calories</p>	 <p>Pint of lager ABV 5.2% 3 UNITS 244 calories</p>	 <p>Pint of cider ABV 5.3% 3 UNITS 194 calories</p>	 <p>Bottle of wine ABV 13.5% 10 UNITS 510 calories</p>

Alcohol guidelines - pregnancy



The new guidelines bring the rest of the UK in line with Scotland and recommend that pregnant women should not drink at all!

The CMO guideline states that:

- If you are pregnant or planning a pregnancy, the safest approach is **not to drink alcohol at all**, to keep risks to your baby to a minimum.
- Drinking in pregnancy can lead to long-term harm to the baby, with **the more you drink the greater the risk**.

NHS A&A: 50% - 60% of women drink at some point in pregnancy (post-natal data)



Alcohol use in Pregnancy



A study published in The Lancet (2017) concludes...

The five countries with the highest estimated prevalence of alcohol use during pregnancy were

- Ireland (60.4%, 42.8–76.8)
- Denmark (45.8%, 30.9–61.2)
- Belarus (46.6%, 42.4–50.7)
- **UK (41.3%, 32.9–49.%) #4!**
- Russia (36.5%, 95% CI 18.7–56.4)

...all of which belong to WHO EUR



Alcohol and pregnancy



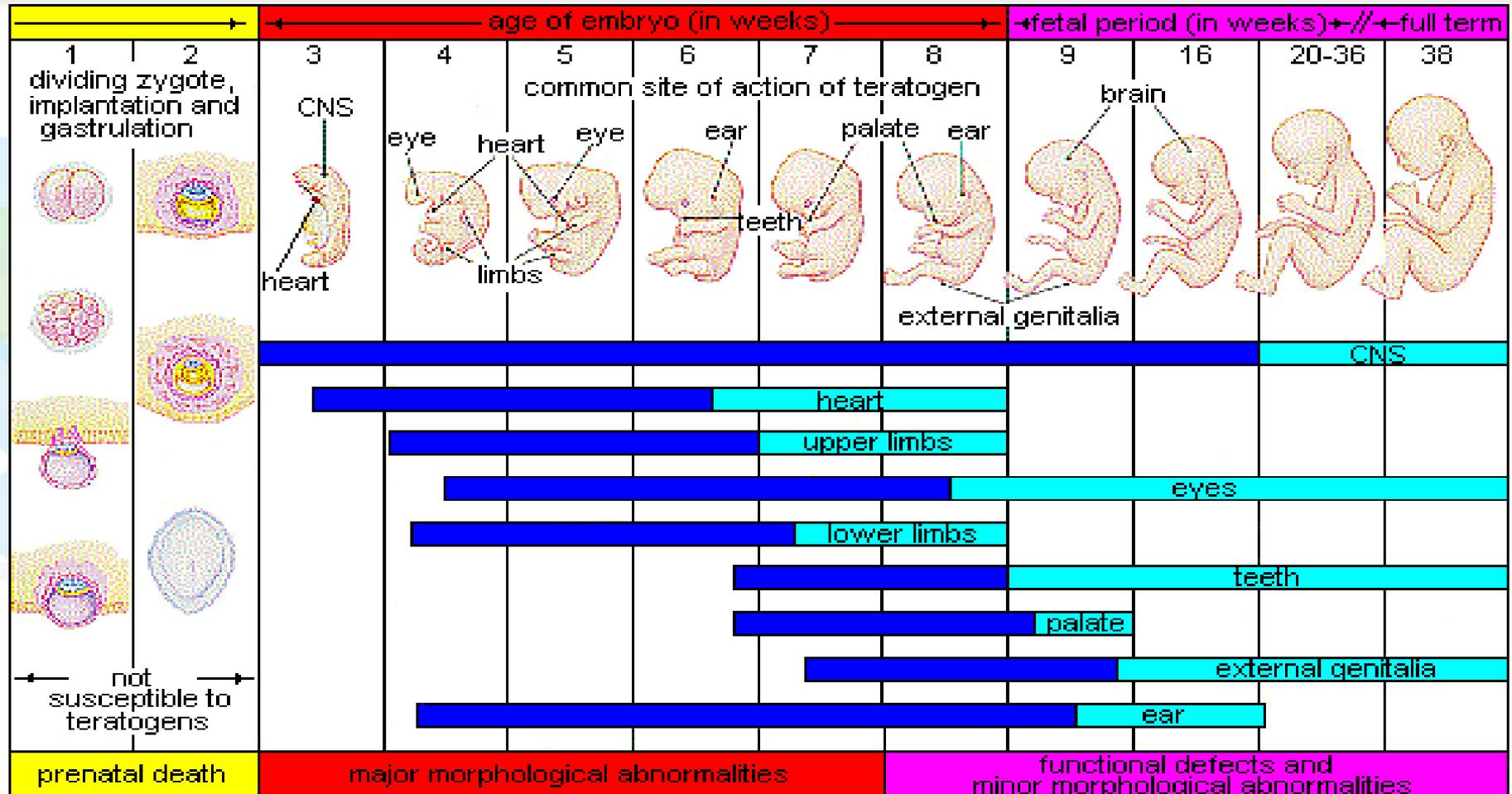
- Alcohol is a teratogen and passes freely through the placenta
- The fetus is completely unprotected from alcohol circulating in its blood system
- Alcohol can destroy/change brain cells and damage the nervous system and other organs

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

American Institute of Medicine Report to Congress, 1996



Fetal Development



To summarise.....



- Binge drinking and alcohol consumption by women is increasing
- Alcohol is a poison against which the developing fetus has no defence
- Alcohol in-utero may cause brain damage
- Severity of damage is linked to frequency of high dose drinking/stage of pregnancy
- No two children are affected the same
- Damage may occur before pregnancy confirmed as most pregnancies are unplanned
- Damage is permanent and irreversible



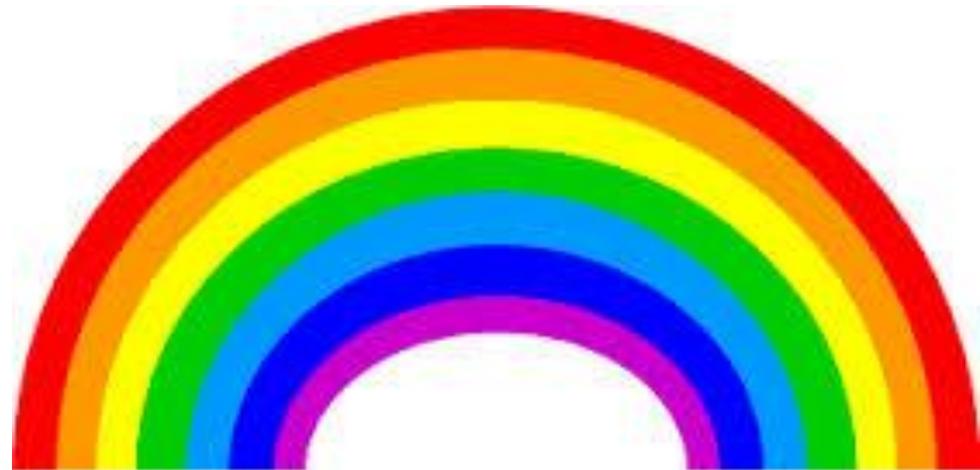
But is preventable!

What is FASD?

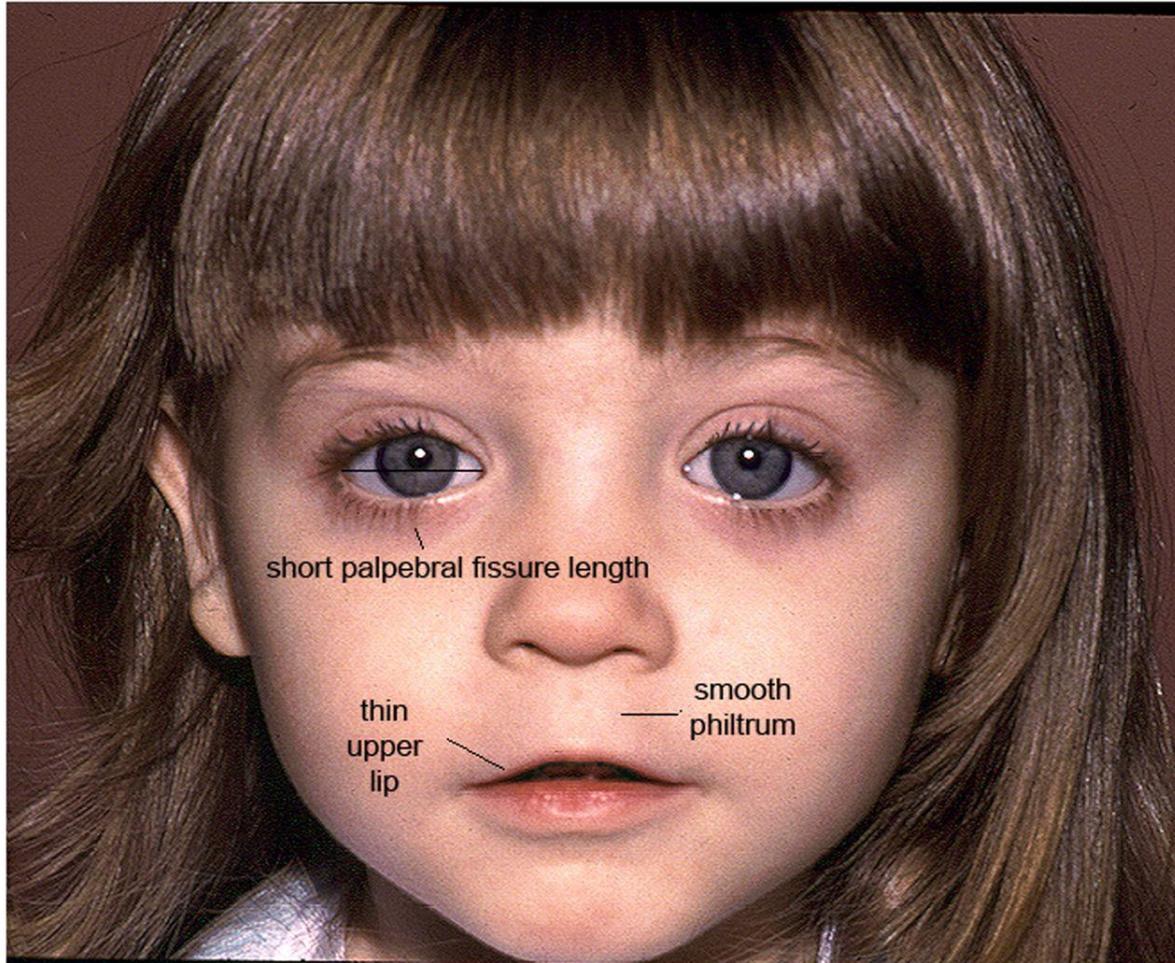


A spectrum of lifelong acquired brain injuries :

- Congenital abnormalities in the structure, size, growth and/or function of the brain and central nervous system.
- Difficulties with development, learning and/or behaviour.
- *May not be detected at birth but can become apparent later in life and carries lifelong implications.*



Facial Features



Only 10% of FASD will have facial features

Facial Features



FAS (<10% of cases)

- NOT ALL INDIVIDUALS WILL HAVE FACIAL FEATURES
- THIS DOES NOT MEAN THAT THEY HAVE NOT BEEN AFFECTED
- FACIAL FEATURES ATTENUATE WITH AGE

Nine brain domains affected by FASD



→ 'Patchy' cognitive profile with a disorganised brain

→ Highly variable from individual to individual



Prevalence



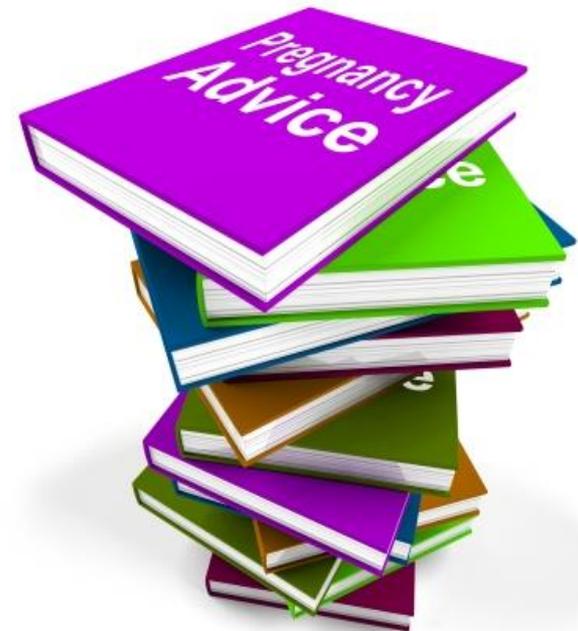
“Alcohol is the most common cause of neuro-disability in the Western world”



Prevalence in Scotland



- Twice as prevalent as autism (autism 1:100)
- FASD likely to be more like **2-5%**
- With 58,592 live births in Scotland (2011), presents potential of:
585 - 2,930 children with Fetal Alcohol Spectrum Disorder born each year.



Prevalence in the care system



- **73-80%** of children with full-blown FAS are in foster or adoptive placement [Burd, 2001]
- FASD is **10-15 times** more prevalent in the foster care system than in the general population.[*Streissguth 1998*]
- Current discussions in literature in relation to the need to screen individuals who have a history of being in care.

Prevalence in CJS



Individuals with FASD are over-represented in the criminal justice system

- FASD youth 19-40 times more likely to be in criminal justice system (Malbin, 2004; Popova et al, 2011).
- 23% of youth forensic inpatients affected by FASD (Fast et al, 2009)
- 60% of FASD-affected individuals over 12yrs old have criminal histories (Streissguth et al., 1996; Streissguth et al, 2004; Brown et al, 2010).

Prevalence in CJS



- FASD among the inmate population est. 28 x higher than in general population (MacPherson 2011)
- 50% of adolescents and adults with FASD displayed inappropriate sexual behaviour (Streissguth et al, 2004)
- 50% of individuals with an FASD have a history of confinement in a jail, prison, residential drug treatment facility, or psychiatric hospital (Streissguth et al, 2004).
- Average age of CJ involvement is 12.8yrs old (Streissguth et al, 2004).

Nine brain domains affected by FASD



“Youth and adults with an FASD have a form of brain damage that may make it difficult for them to stay out of trouble with the law”

What we need to remember...



Individuals with FASD are.....

- Sociable
- Persistent and committed
- Strong sense of fairness
- Caring, affectionate, sensitive & loving
- Loyal and kind
- Fun-loving, spontaneous, great sense of humour
- Can be musical, artistic and athletic



Nine brain domains affected by FASD



Nine brain domains affected by FASD



Neurodevelopmental Deficits become Criminal Risk

Neurodevelopmental profiles impact on:

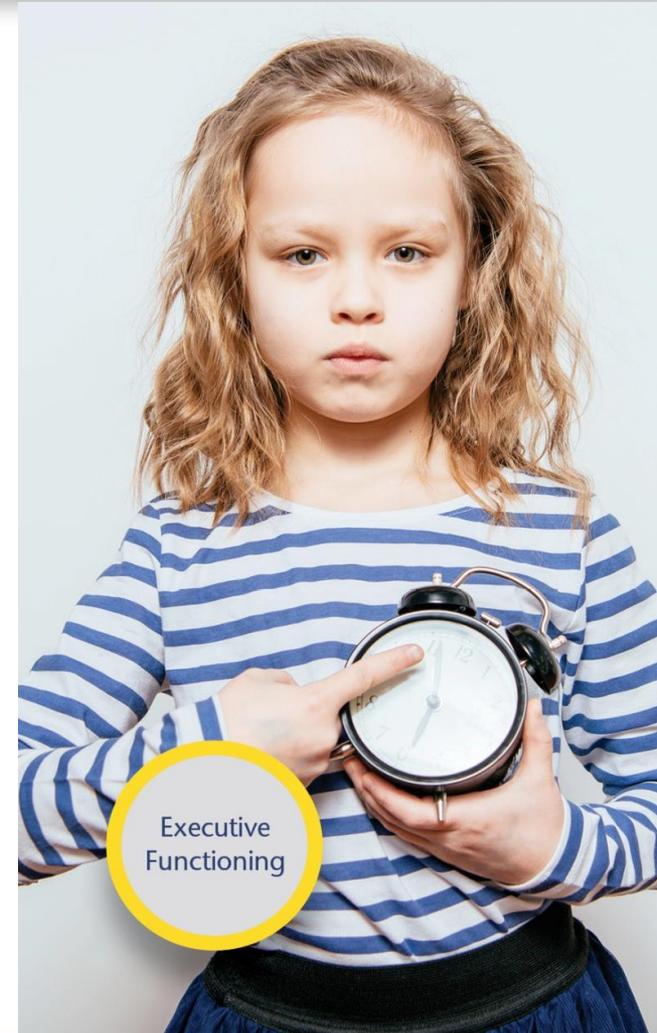
- What crimes are committed
- How crimes are committed
- How criminal justice colleagues should interact with offenders
- How offenders are supported to navigate the court, prison, and parole systems
- Rehabilitation / Compensatory strategies

Executive Functioning



Difficulties:

- Planning, sequencing, problem solving & organisation
- Controlling emotions; may be impulsive
- Transition and change and managing time
- Understanding cause & effect, consequences of actions and don't learn from mistakes
- Understanding concepts & abstract ideas



Considerations for CJS



- Illogical crime with high detection risk
- Lack of impulse control → tendency toward explosive episodes
- Poor exit strategies
- Poor concept of time
- May find it difficult to distinguish right from wrong
- Trouble understanding & linking cause / effect
- Issues understanding ownership (abstract concept)
- Difficulty delaying gratification
- Difficulty making good judgments

- Increased likelihood of recidivism

Sensory and Motor



Difficulties:

- Sensitivity to light, sound, taste, smells & textures
- May over/under respond to stimulation
- May be unable to make sense of what is going on around them
- Difficulty with fine and gross motor skills



Sensory
and Motor

Considerations for CJS



- Struggle with crowded environments, police stations, sirens
- Atypical reaction to police contact
- Resulting stress/anxiety impacts on behaviour and reduces understanding
- May appear intoxicated when they are not

Academic Skills



Difficulties:

- Maths, reading, time & money
- Comprehension, organisation & abstract concepts
- Completing age appropriate academic tasks
- Learn better with visual or hands on approach



Academic
Skills

Considerations for CJS



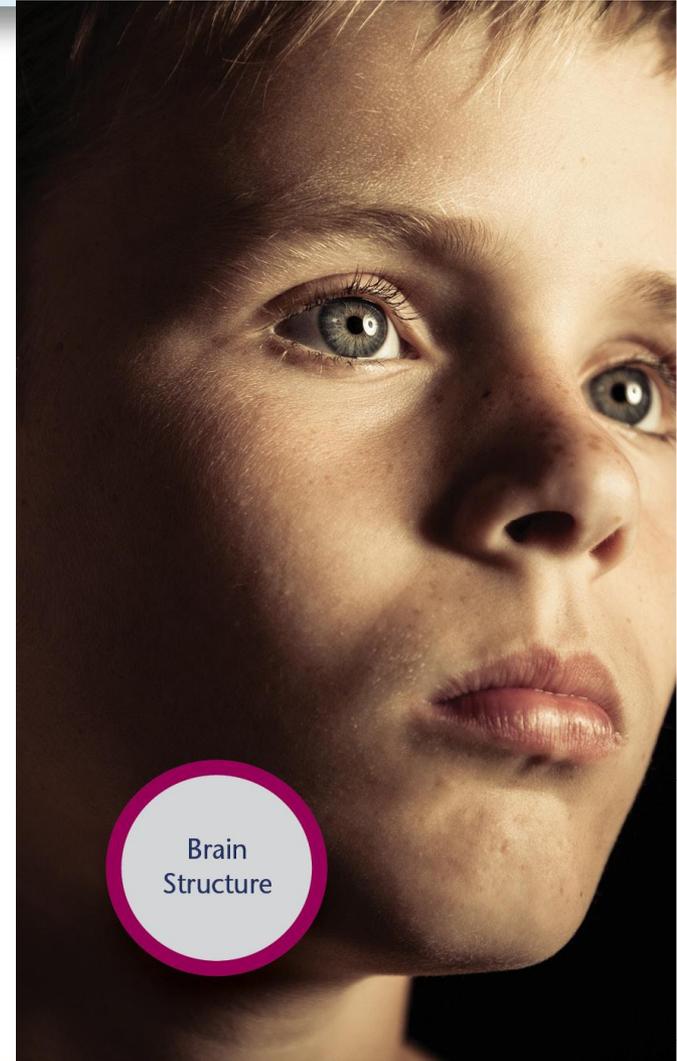
- Most CJS information/paperwork is word-heavy
- Visual materials facilitate better understanding
- Ability to engage in education settings is compromised

Brain Structure



Difficulties:

- Smaller brain
- Small head circumference
- Absent or partial absence of corpus callosum
- Neurologic problems (e.g. seizures)



Brain
Structure

Structure Considerations for CJS



- Small heads and stature do not occur in all FASD cases
- They occur with many other developmental difficulties
- Highly related to maternal nutrition and individuals' nutrition
- Related to other drug exposures in-utero

Living & Social Skills



Difficulties:

- Inappropriate responses in social situations
- Misunderstand social cues and personal boundaries
- Socially vulnerable – easily taken advantage of
- Difficulty seeing things from another's perspective
- Socially & emotionally immature....behave younger than actual age



Living and
Social Skills

Living & Social Skills



Difficulties:

- Difficulty managing independent living
- Difficulty with functional life skills – own timeline, cooking, dressing appropriately, managing money



Considerations for CJS



- Vulnerable to peer pressure (more sophisticated co-defendants)
- Do not know how to interact within criminal justice system or communicate appropriately with workers.
- Can easily waive rights
- Vulnerable to suggestion and misunderstanding of judicial processes
- Incarceration can incur victimisation / exploitation – safer in juvenile
- External supports are often needed for behaviour change (i.e. external brain needed to compensate)

Executive Function & Living Skills

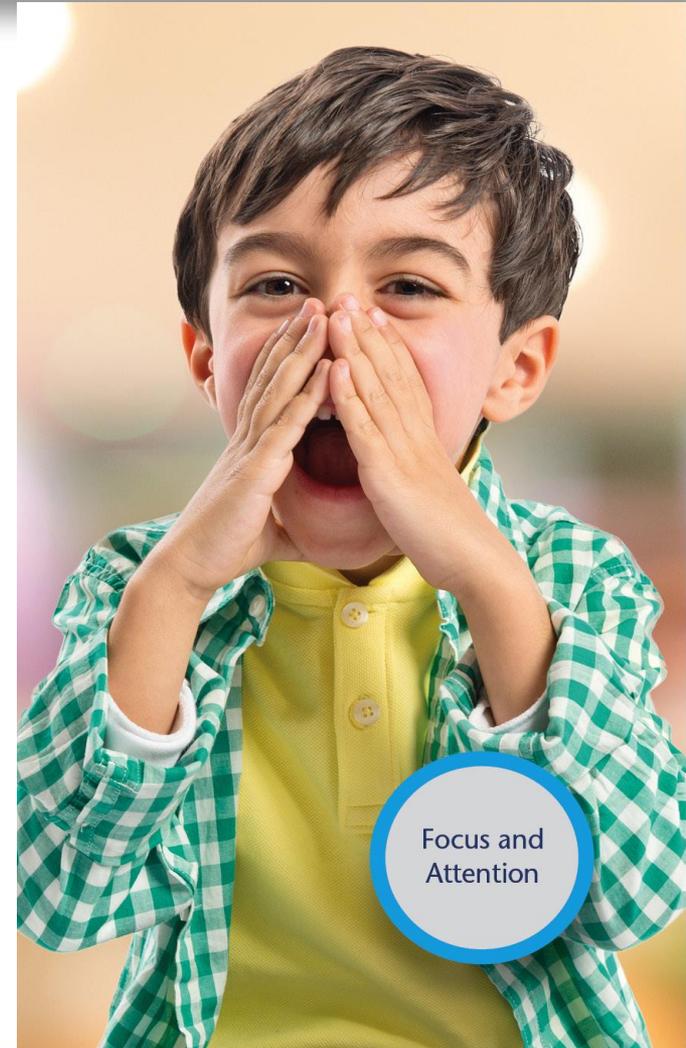


- Executive function strongly related to daily functioning
- Better predictor of functioning than cognition, because executive function controls how a person can wield their intelligence.
- Don't rely on a cognitive assessment only – most -1SD below the average on cognition but -2SD+ on executive functioning.

Focus and Attention

Difficulties:

- Easily distracted
- Over stimulated
- Impulsiveness
- Inattentive
- Hyperactive
- 'Can't sit still'
- Hearing impairment/auditory processing problems



Considerations for CJS



- May not be able to inhibit behaviour
- Cannot attend to lengthy instruction or rules
- May seem disinterested and disengaged in a police or court setting

Cognition



Difficulties:

- Thinking & reasoning
- Attention, learning, memory, planning & organisation.
- Problem solving and following complex instructions.



Considerations for CJS



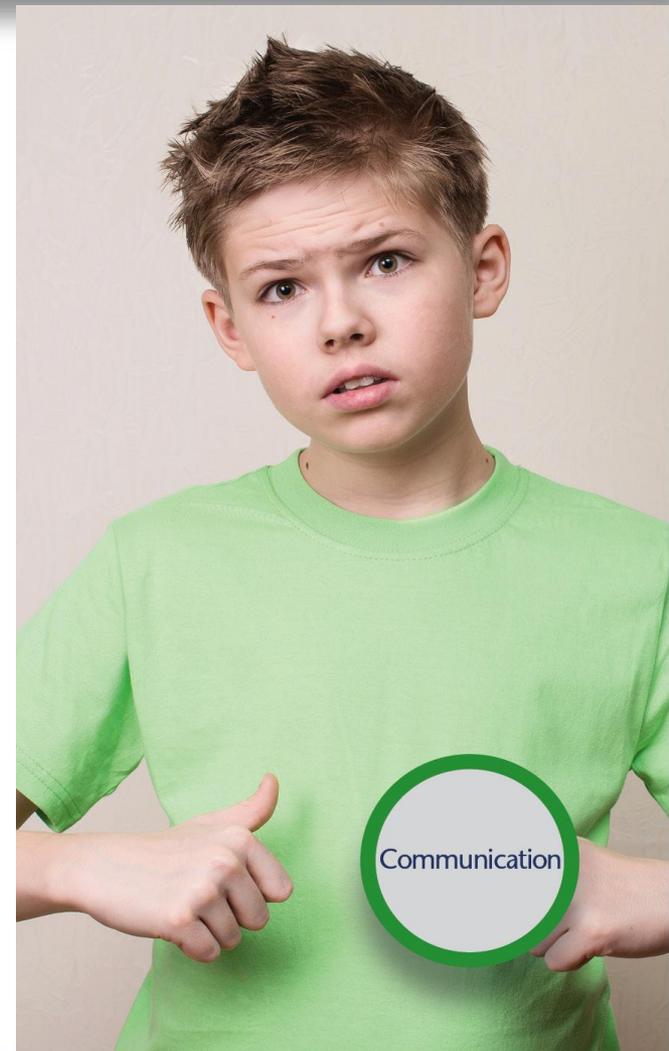
- May describe offence as focused only on objective
- Struggle to make informed decisions on basic legal process (unable to fully understand the charges or participate meaningfully in their own defence).
- May display rote repetition without understanding
- Slowed processing speed
- Particular deficits in working memory
- Difficulty understanding consequences / to show empathy & true remorse

Communication



Difficulties:-

- Delayed language milestones for age
- May speak well but not grasp full meaning
- Difficulty understanding lengthy conversations
- Difficulty following instructions
- Can repeat instructions but then be unable to follow them through



Considerations for CJS

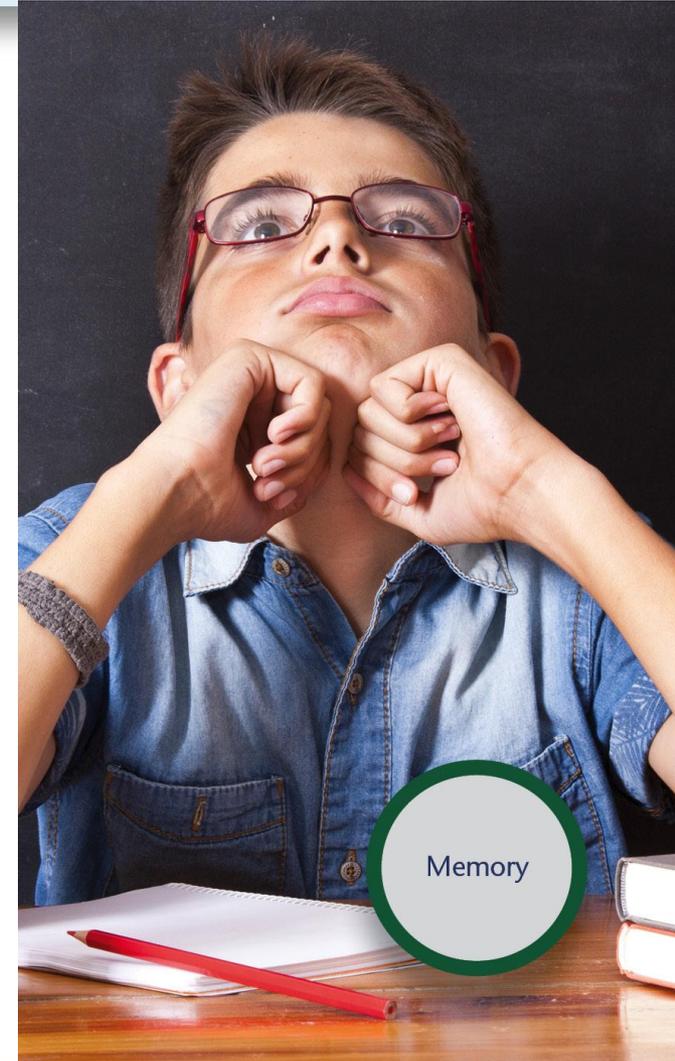


- Language expression can be much higher than comprehension abilities
- Can 'talk the talk but can't walk the walk'
- May not fully understand words / phrases e.g. Those used in legal proceedings / charges against them
- Pausing before answering for processing time can look like planning / lying
- May struggle to understand the rules for sentencing or probation as the courts use advanced language

Memory

Difficulties:

- Long and short term memory
- Verbal, working and visual
- Problems recalling sequences
- Recalling instructions given verbally
- Relatively better visual memory
- Easily forget steps in normal daily routine
- Appear to lie but is filling in blanks when unable to remember



Considerations for CJS



- Poor memory, particularly for verbal information.
- Unable to organise thoughts, recall and explain their story chronologically or in sufficient detail
- Vulnerable to confabulation
- May be liable to acquiesce = false confessions.
- May forget rules for court attendance, probation.
- May appear to repeat same mistakes (exec fn)

What you see is NOT always what you get.....



Criminal Justice & Licensing (Scotland) Act, 2010 (Pt 7)



If the person is incapable, by reason of a mental or physical condition, of participating effectively in a trial.

Determined by the ability of the person to

- i) understand the nature of the charge
- ii) understand the requirement to tender a plea to the charge and the effect of such a plea
- iii) understand the purpose of, and follow the course of, the trial
- iv) understand the evidence that may be given against the person

May be considered a 'Vulnerable Witness' (2004)

Associated concerns



As the children with FASD grow older they experience:

- Social difficulties in relating to their peer group and often face a traumatic path through adolescence and beyond
- Involvement with criminal Justice
- Homelessness
- Unemployment
- Dependent living
- Become vulnerable adults

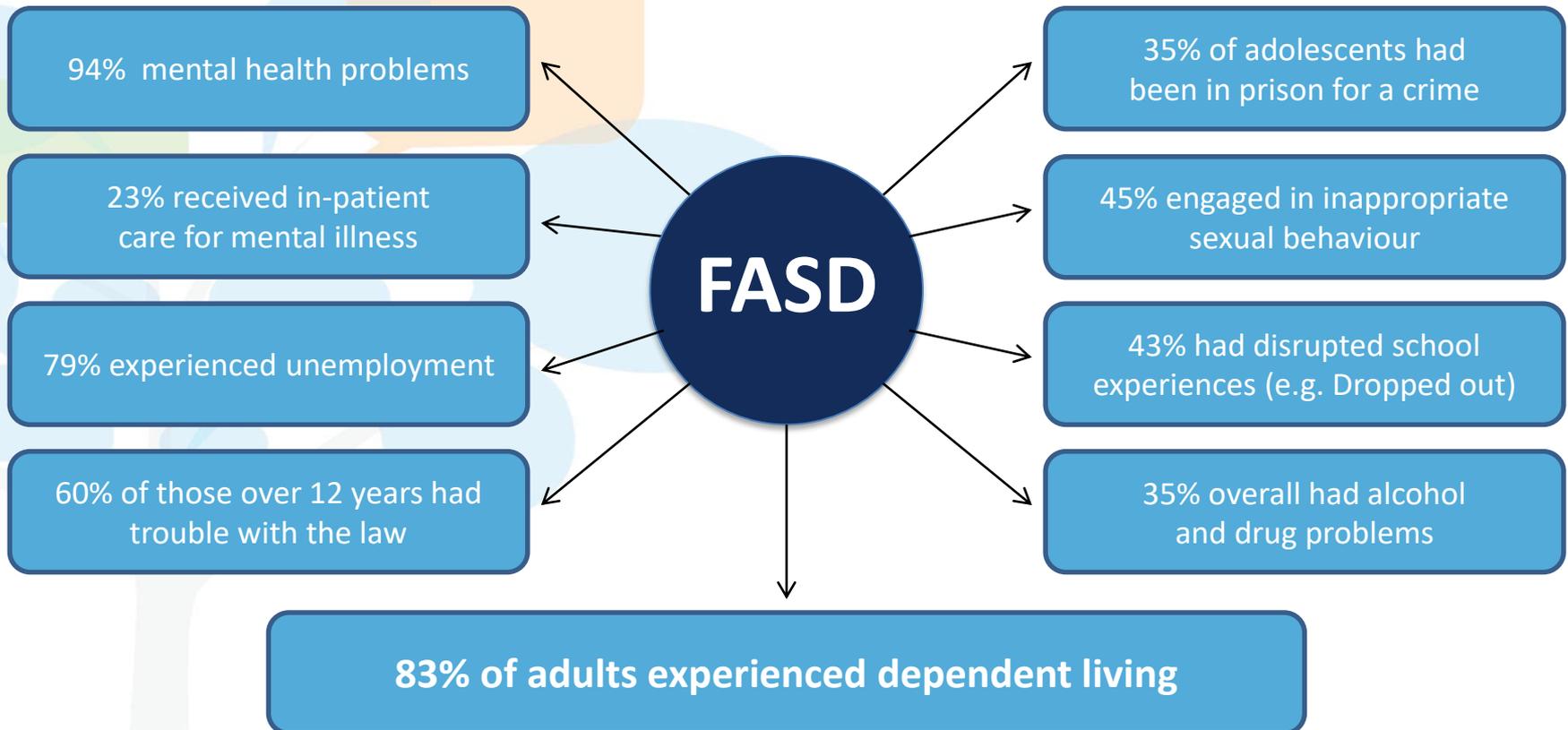
Implications for Recidivism and Rehabilitation



- Sentencing: attorneys may be successful in presenting FASD as a mitigating factor.
- Increased likelihood of recidivism
- Inability to link actions to consequences
- Incarceration may lead to further victimisation and exploitation
- Alternative approaches to sentencing may be more beneficial –
Diversionary processes – Sentencing Circles – Conditional sentences
- court ordered treatment

What if we do nothing?

Study of 500 adults with FASD (*FASD Centre of Excellence, Manitoba 2007*)



What can we do? - FASD



- Better training to identify and respond to FASDs
- Early Detection and Intervention
- Early and ongoing evaluation of children suspected to have a FASD - neuropsychological profile, do not stop at cognitive assessment.
- Social skills interventions - capitalise on neural plasticity of child's brain
- Support and training for parents/caregivers
- Develop guidelines for dealing with FASD
- Pathways for diagnosis and treatment
- More research into FASD (Douglas, Hammill, Russell, & Hall, 2012)

What can we do? - Strategies



- Early intervention to prevent children with a FASD entering or returning to the criminal justice system
- Harness strengths including visual memory, and hands on learning (experiential) - provide written information, in simple language / pictorial formats and REPEAT
- Use open, non leading questioning & plenty of time to avoid acquiesced responses
- Simple, concrete language and rules
- Visual planners, reminders, memory aids
- Immediate and relevant consequence and rewards

What can we do? - CJ



- A consistent judge to follow a child's case
- Children's lawyer experienced in FASD
- Intense supervision and structured support – external brain
- Identify qualified experts to consult to court
- Awareness of mental health risk in FASD – overlap of psychiatric, behavioural, motor, learning, and academic difficulties are indicative of 'atypical brain development' (Gilger & Kaplan, 2001).

Conclusions



- Individuals with FASD may often present in the criminal justice system
- Individuals with neurodevelopmental risk factors are misunderstood, with initial hypotheses being largely about behaviour / mental health.
- FASD is a risk factor for crime and recidivism
- FASD requires compensation over rehabilitation
- Early recognition may reduce over-representation of individuals with FASD in criminal justice system
- ?Screening for those within the system?

Recommendations



- All Party Parliamentary Group on FASD
Current Picture of FASD in the UK Today (2015)
 - ‘The Ministry of Justice needs to consider the impact of FASD within the Criminal Justice System’

FASD is everybody’s business

Any questions?



Thank you for attending today.

Remember FASD is a hidden disability and some people may take time to understand.

Please share your knowledge.

Together we can help make sense of FASD.

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